#### **RULEMAKING NOTICE FORM**

Notice Number 2019-34	Rule Number	He-M 519
1. Agency Name & Address:	2. RSA Authority:	RSA 126-G:5
	3. Federal Authority:	
Dept. of Health & Human Services	4. Type of Action:	
<b>Bureau of Developmental Services</b>	Adoption	
105 Pleasant Street, Main Bldg.	Amendment	<u></u>
Concord NH 03301	Repeal	
	Readoption	X
	Readoption w/an	nendment X
5. Short Title: Family Support Services	•	

6. (a) Summary of what the rule says and of any proposed amendments:

He-M 519 specifies a framework for the provision of family support and services to care-giving families with an individual with a developmental disability, acquired brain disorder, or receiving family-centered early supports and services. Additionally, the rule describes the structure, roles, and responsibilities of regional family support councils in advising and collaborating with their local area agencies and the state Family Support Council and in advising the Bureau.

Most of He-M 519 expires on 2/26/19 and is being filed pursuant to RSA 541-A:14-a to prevent expiration. He-M 519.09(b)-(c) effective 2-26-11 (Document 9879-B) are not expiring, but are being included in this proposal so that the proposal as a whole is understandable.

The proposed rules include the following revisions:

- Amending definitions to align with other Departmental He-M rules including adding a definition for "Department", "Partners in Health" and "Special Medical Services".
- Changing the definition of "family" to no longer require that the primary care-giver reside in the same household as the individual, which will be beneficial to families and individuals served.
- Revising the permissible forms of financial assistance, as the language was limiting, and permitting this type of assistance to be provided in the form of gift cards, or by the direct payment for a good or service to assist a family. This will enable flexibility with providing financial assistance.
- Strengthening policies of the regional council, and requiring that the agreement between the Family Support Council and the area agency be in writing.

- Adding provisions in He-M 519.05 to ensure that confidentiality of families and individuals needs and services is properly maintained.
- Adding provisions to require designated staff:
  - To ensure that individuals and families have accessed all other available funding and community resources prior to requesting funding from the Council;
  - o To require the facilitation and distribution of family support funds approved for distribution by the Family Support Council; and
  - o To provide information or referral to Partners in Health if required by the Partner's family support coordinator, individual, or family.
- Deleting He-M 519.09(f) because the rule already states that waivers shall be granted within 30 days.
- 6. (b) Brief description of the groups affected:

These rules affect families receiving or who will be eligible to receive supports and services under these rules. Area Agencies providing services, and family support councils that advise and collaborate with area agencies.

6. (c) Specific section or sections of state statute or federal statute or regulation which the rule is intended to implement.

Rule	State Statute Implemented
He-M 519.01 - 519.04	RSA 126-G:3
He-M 519.05 - 519.07	RSA 126-G:4
He-M 519.08 - 519.09	RSA 126-G:3

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TTY/TDD Access: Relay NH 1-800-735-2964 or dial 711 (in NH)

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	The proposed rules may be viewed and downloaded at: <a href="http://www.dhhs.nh.gov/oos/aru/comment.htm">http://www.dhhs.nh.gov/oos/aru/comment.htm</a>				
8.		or submission of materials in writing or, if March 25, 2019	practicable for the agency, in the electronic format		
	⊠Fax	⊠E-mail	Other format (specify):		

9.	Public hearing scheduled for:						
			ate and Time:	•	· · · · · · · · · · · · · · · · · · ·	19 11:00 AM Auditorium, 129 Pleasant St., Concord, NH 03301	
10.	Fis	Fiscal Impact Statement (Prepared by Legislative Budget Assistant)					
		FIS#	19:0	18	_ , dated _	February 13, 2019	
	1.	Comp	arison of the c	osts of the	proposed rul	le(s) to the existing rule(s):	
		There	is no difference	in cost wh	en comparing	g the proposed rules to the existing rules.	
	2. Cite the Federal mandate. Identify the impact on state funds:					act on state funds:	
	No federal mandate, no impact on state funds.						
	<ul> <li>3. Cost and benefits of the proposed rule(s):</li> <li>A. To State general or State special funds: None.</li> <li>B. To State citizens and political subdivisions:</li> </ul>						
			None.				
		C.	To independ	ently owne	ed businesses	:	
			None.				
11.	Statement Relative to Part I, Article 28-a of the N.H. Constitution:						
	The proposal does not mandate any fees, duties or expenditures on the political subdivisions of t state, and therefore does not violate Part I, Article 28-a of the N.H. Constitution.						

Initial Proposal 1/30/2019 1

#### CHAPTER He-M 500 DEVELOPMENTAL SERVICES

#### Readopt He-M 519.01, effective 2-26-11 (Document #9879-A), cited and to read as follows:

#### PART He-M 519 FAMILY SUPPORT SERVICES

He-M 519.01 <u>Purpose</u>. The purpose of this part is:

- (a) To establish a framework for the provision of supports and services to care-giving families with an individual member who:
  - (1) Has a developmental disability or acquired brain disorder; or
  - (2) Is eligible for family-centered early supports and services pursuant to He-M 510.06;
- (b) To describe the structure, roles and responsibilities of regional family support councils in advising and collaborating with their local area agencies; and
- (c) To describe the structure, roles, and responsibilities of the state family support council in supporting regional councils and in advising the bureau.

# Readopt with amendment He-M 519.02, effective 2-26-11 (Document #9879-A), to read as follows:

He-M 519.02 Definitions.

- (a) "Acquired brain disorder" means a disruption in brain functioning that:
  - (1) Is not congenital or caused by birth trauma;
  - (2) Presents a severe and life-long disabling condition which significantly impairs a person's ability to function in society;
  - (3) Occurs prior to age 60;
  - (4) Is attributable to one or more of the following reasons:
    - a. External trauma to the brain as a result of:
      - 1. A motor vehicle incident;
      - 2. A fall;
      - 3. An assault; or
      - 4. Another related traumatic incident or occurrence;
    - b. Anoxic or hypoxic injury to the brain such as from:
      - 1. Cardiopulmonary arrest;
      - 2. Carbon monoxide poisoning;
      - 3. Airway obstruction;
      - 4. Hemorrhage; or
      - 5. Near drowning;

- c. Infectious diseases such as encephalitis and meningitis;
- d. Brain tumor;
- e. Intracranial surgery;
- f. Cerebrovascular disruption such as a stroke;
- g. Toxic exposure; or
- h. Other neurologic disorders such as Huntington's disease or multiple sclerosis which predominantly affect the central nervous system; and
- (5) Is manifested by:
  - a. Significant decline in cognitive functioning and ability; or
  - b. Deterioration in:
    - 1. Personality;
    - 2. Impulse control;
    - 3. Judgment;
    - 4. Modulation of mood; or
    - 5. Awareness of deficits.
- (b) "Area agency" means-"area agency" as defined in RSA 171-A:2, Ian entity established as a non-profit corporation in the state of New Hampshire and designated by the commissioner to provide services to persons with developmental disabilities or acquired brain disorders in the area in accordance with RSA 171-A:18 and He M 505.
- (c) "Bureau" means the bureau of developmental services of the department of health and human services.
  - (d) "Bureau administrator" means the chief administrator of the bureau of developmental services.
  - (e) "Commissioner" means the commissioner of the department of health and human services.
  - (f) "Department" means the New Hampshire department of health and human services.
- (gf) "Developmental disability" means "developmental disability" as defined in RSA 171:A:2, V, namely "a disability:
  - (a) Which is attributable to intellectual disability, cerebral palsy, epilepsy, autism, or a specific learning disability, or any other condition of an individual found to be closely related to intellectual disability as it refers to general intellectual functioning or impairment in adaptive behavior or requires treatment similar to that required for intellectually disabled individuals; and
  - (b) Which originates before such individual attains age 22, has continued or can be expected to continue indefinitely, and constitutes a severe handicap to such individual's ability to function normally in society."

- (hg) "Family" means a group of 2 or more persons that:
  - (1) Is related by ancestry, marriage, or other legal arrangement;
  - (2) Has one member who is the primary caregiver of the individual in (3) below; Is living in the same household; and
  - (3) Has at least one member who is an individual as defined in (ii) below.
- (ih) "Family support" means those services, activities and interventions, enumerated in He-M 519.04 (c), that are identified by a family to assist that family to remain the primary caregiver of an individual.
- (ji) "Individual" means a person with a developmental disability or acquired brain disorder who is eligible or conditionally eligible pursuant to He-M 503.03 or He-M 522.03 or a child, through age 2, who is eligible for family-centered early supports and services pursuant to He-M 510.06.
- (k) "Partners in Health (PIH)" means "partners in health" as defined in He-M 523, namely PIH means a New Hampshire community-based program of family support for young adults and families.
- (Li) "Region" means "area" as defined in RSA 171-A:2, I-a, namely a geographic region established by rules adopted by the commissioner for the purpose of providing services to developmentally disabled persons a geographic area designated pursuant to He-M 505.04 for the purpose of providing services to persons with developmental disabilities or acquired brain disorders and their families.
- (mk) "Respite" means the provision of short-term and care, in accordance with He-M 513, periodic services for an individual, in or out of the individual's family home, for the temporary relief and support of the family with whom the individual lives.
- (l) "Service agreement" means a written agreement between a family and an area agency that describes the services that the family will receive.
- (n) "Special Medical Services (SMS)" means "special medical services" as defined in He-M 520 namely, the bureau of special medical services that operates the Title V program for children and youth with special health care needs.
- (om) "Supports and services" means a wide range of activities that assist families in developing and maximizing the families' abilities to care for individuals and meet their needs in a flexible manner.

# Readopt He-M 519.03, effective 2-26-11 (Document #9879-A), to read as follows:

He-M 519.03 Eligibility. A family shall be eligible for family support services if such family has:

- (a) An individual member from birth through age 2 who is eligible for family-centered early supports and services pursuant to He-M 510.06; or
- (b) An individual member age 3 or older who has a developmental disability or an acquired brain disorder pursuant to He-M 503.03 or He-M 522.03.

Readopt with amendment He-M 519.04-519.06, effective 2-26-11 (Document #9879-A), to read as follows:

He-M 519.04 Supports and Services.

(a) Family support services shall:

- (1) Focus on the entire family:
- (2) Recognize and value the family's strengths and competencies;
- (3) Respect the family's approach to making decisions regarding provision of supports and services:
- (4) Create and emphasize opportunities for families to build relationships in their communities;
- (5) Maximize the family's control over the provision of supports and services;
- (6) Identify resources and supports and services that are flexible, individualized, and responsive to the changing needs of the family;
- (7) Respect the family's cultural and ethnic beliefs, traditions, personal values, and lifestyles;
- Empower families through educational opportunities and wide dissemination of information: and
- (9) Promote family involvement in all levels of planning, policy-making, and monitoring of the service system.
- (b) In addition to offering area agency programs or funds to provide supports and services, family support staff shall explore, identify, and assist families to access community resources, both formal and informal, as available.
- (c) Family support shall include, but not be limited to the following be comprised of supports and services such as:
  - (1) Information and referral;
  - (2) Assistance to identify and assess the family's own strengths, needs, and goals;
  - (32) Identification of, and assistance to access, community resources and supports;
  - (43) Assistance with transition in and out of services;
  - (54) Crisis intervention and emotional support;
  - (65) Advocacy for accessing supports and services;
  - (76) Opportunities for fFamily networking;
  - (87) Assistance to accessing respite care;
  - (98) Assistance to accessing environmental modifications of the family's home and the family's vehicle;
  - (109) Promotion of inclusive social and recreational opportunities;
  - $(1\underline{10})$  Conferences and workshops in response to families' requests;
  - (121) Community outreach, education, and development to promote understanding and support for families as well as individuals with disabilities;
  - (132) Financial assistance, as available, in the form of cash subsidies, vouchers, or reimbursements provided that this assistance is:

- a. Related to supporting a family to care for an individual member in the family home,
- b. Consistent with the established policies of the area agency and, if applicable, the regional family support council as required by He-M 519.05(c)(5); and
- (143) Other supports and services that assist a family in providing care for an individual member in the family home.

# He-M 519.05 Regional Family Support Council.

- (a) Each region shall have a family support council that shall act as an advisory body to the area agency.
  - (b) A regional family support council shall:
    - (1) Be composed of a minimum of 5 voting members;
    - (2) Have members who are either family members or individuals;
    - (3) Have no voting member who is an employee of either the area agency or the family support council; and
    - (4) Have membership that is representative of the various ages and geographical locations, and overall diversity of the individuals and families served in the region.
- (c) Regional family support councils shall establish and maintain policies that address, at a minimum, the following:
  - (1) Membership, recruitment, rotation, and term limits on the council;
  - (2) A process for determining the chairperson, the state council delegate, and any other positions such as the council representative to the area agency board of directors, and any other positions;
  - (3) Orientation and mentoring of all council members;
  - (4) A formal written agreement between the council and the area agency that identifies:
    - a. The parties' relationship, roles, and responsibilities;
    - b. The process to be used in resolving any conflicts which might arise between the parties;
    - c. The involvement of the council in the selection and evaluation of the performance of the family support staff; and
    - d. The family support representative on the area agency management team and the mechanism for direct communication between this person and the council;
    - e. The family support council's obligation to comply with all confidentiality requirements as set by federal authorities, the department, or the area agency; and

- f. The process for sharing contact information for families in the region with the family support council for the purpose of outreach, advocacy, or information.
- (5) Processes used to disperse family support council funds and other resources including ensuring family privacy in the application and fund allocation process; and
- (6) A mechanism for the council to be involved in the area agency monitoring of supports and services provided to families.
- (d) The regional family support councils shall coordinate their efforts with other local public and private entities that serve children, adults, and families, including but not limited to early supports and services providers, PIH, and SMS that serve children and their families.

## He-M 519.06 Family Support Staff.

- (a) Each area agency shall designate not less than one full-time position as the family support coordinator or director.
- (b) The qualifications and duties of the staff person designated pursuant to (a) above shall be identified by a job description designed jointly by the regional family support council and the area agency.
- (c) The designated staff person shall perform all duties in his or her job description including, at a minimum:
  - (1) Representing the ideas and concerns of families and of family support staff to the area agency executive director and at management team meetings;
  - (2) Promoting the values of family support as listed in He-M 519.04 (a) in area agency activities and initiatives;
  - (3) Acting as the primary liaison with the council and regularly attending council meetings;
  - (4) Providing information to the council regarding family support activities so that the council:
    - a. Understands families' needs;
    - b. Can act on families' needs; and
    - c. Is involved in the area agency monitoring of regional supports and services; and
  - (5) Ensuring that an individual or family has accessed all other available funding and community resources prior to requesting funding for family supports from the council;
  - (6) Facilitating the distribution of family support funds approved for distribution by the family support council;
  - (7) Providing information or referral to PIH if requested by the PIH family support coordinator, or the individual, or family; and
  - (85) Providing feedback to other family support staff from the council and the management team.
  - (d) Family support staff shall:
    - (1) Provide, or assist families in accessing, family supports and services;

- (2) Solicit support for families from community groups, foundations, and other sources as needed;
- (3) Plan and develop service-agreements with each family that document the supports in He-M 519.04 (c) that will be provided;
- (4) Maintain records regarding the supports and services provided to each individual or family;
- (54) Maintain data that specifies the type and frequency of family supports and services provided; and
- (65) Report data collected pursuant to (4) and (5) above to the bureau on a quarterly basis.

## Readopt He-M 519.07, effective 2-26-11 (Document #9879-A), to read as follows:

He-M 519.07 Regional Family Support Plan.

- (a) Each regional family support council shall contribute to the development of the area plan prepared pursuant to He-M 505.03 (t)-(u).
- (b) To satisfy the requirements of He-M 505.03 (u)(2), the regional family support council's contribution pursuant to (a) above shall consider:
  - (1) The priorities of families residing throughout the region for supports and services; and
  - (2) Strategies to address these priorities.

#### Readopt with amendment He-M 519.08, effective 2-26-11 (Document #9879-A), to read as follows:

He-M 519.08 State Family Support Council. The state family support council shall:

- (a) Be comprised of one voting delegate appointed by each of the 10 regional family support councils;
  - (b) Be assisted by the bureau family support administrator or designee and bureau support staff;
  - (c) Elect a new chairperson at least every 2 years;
  - (d) Hold meetings every other month to discuss agenda items formulated by members of the council;
  - (e) Be a forum for exchanging, sharing, and distributing information to each regional council;
- (f) Be an avenue for arbitration and mediation of conflict resolution between area agencies and regional councils when requested by both parties and after processes identified pursuant to He-M 519.05(c)(4)b. have been exhausted; and
  - (g) Provide information and feedback on issues and concerns of regional councils to the bureau.

# Readopt with amendment He-M 519.09, effective 2-26-11 (Document #9879-A & B), to read as follows:

He-M 519.09 Waivers.

(a) An area agency or regional family support council may request a waiver of specific procedures outlined in He-M 519 by completing and submitting to the department(b) The entity requesting a waiver shall:

(1) Complete the form entitled "NH Bureau of Developmental Services Waiver Request" (September 2013 edition); and

- (b2) A completed waiver request form shall iInclude signatures by the family support council chairperson or designee indicating agreement with the request and the area agency's executive director or designee recommending approval of the waiver.
  - (c) A waiver request shall be submitted to:

Department of Health and Human Services

Bureau of Developmental Services

Hugh J. Gallen State Office Park

105 Pleasant Street, Main Building

Concord, NH 03301

- (de) All information entered on the forms described in (ab) above shall be typewritten or otherwise legibly written.
  - (ed) No provision or procedure prescribed by statute shall be waived.
- (fe) The request for a waiver shall be granted by the commissioner or his or her designee within 30 days if the alternative proposed by the requesting entity meets the objective or intent of the rule and it:
  - (1) Does not negatively impact the health or safety of the individual(s); and
  - (2) Does not affect the quality of services to individuals.
- (f) The determination on the request for a waiver shall be made within 30 days of the receipt of the request.
- (g) Upon receipt of approval of a waiver request, the requesting entity's subsequent compliance with the alternative provisions or procedures approved in the waiver shall be considered compliance with the rule for which waiver was sought.
- (h) Waivers shall be granted in writing for a specific duration not to exceed 5 years except as in (i) below.
- (i) An area agency or regional family support council requesting entity may request a renewal of a waiver from the bureau. Such request shall be made at least 90 days prior to the expiration of a current waiver.
- (j) A request for renewal of a waiver shall be approved in accordance with the criteria specified in (e) above.

# **APPENDIX**

Rule	State Statute Implemented
He-M 519.01 - 519.04	RSA 126-G:3
He-M 519.05 - 519.07	RSA 126-G:4
He-M 519.08 - 519.09	RSA 126-G:3